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ABSTRACT

This paper presents an overview of the developmental disabilities associated with pediatric Human Immunodeficiency Virus (HIV) infection, and examines efficacious practices for assessment and intervention programming. The focus population is early childhood into school age. The paper describes the complex array of challenges presented by these children, and cites statistics on the incidence of acquired immunodeficiency syndrome in pediatric populations. Symptoms of HIV-related infection are described, such as compromised health and developmental delays in motor skills, language, and cognitive ability. The purposes of developmental assessment are outlined, and challenges in assessing the pediatric HIV population are discussed in terms of child factors, family factors, and instrument or evaluator factors. For those carrying out assessment procedures special considerations are called for, such as being concise, being flexible, and conducting frequent assessments. Selection of assessment instruments should be based on the child's age and level of functioning and on professional judgment. A comprehensive school-based developmental program combining such services as regular and special education, physical therapy, speech therapy, occupational therapy, health and medication monitoring by a nurse, counseling, behavior management, and social work is recommended. (Contains 20 references.) (JDD)

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PEDIATRIC HIV INFECTION AND DEVELOPMENTAL DISABILITIES

American Association On Mental Retardation
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Presentation Summary:
The purpose of this workshop is to present an overview of the developmental disabilities associated with pediatric HIV infection, and efficacious practices for assessment and intervention programming. The primary focus population will be early childhood into school age.

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INTRODUCTION

New populations of special needs children obviously challenge our educational system, but no group is perceived by educational personnel as having such a complex array of challenges as children with the Human Immunodeficiency Virus (HIV). Issues frequently associated with providing services to children with HIV infection in a school setting include: HIV transmission concerns, special programming to accommodate fluctuating developmental status and compromised health, confidentiality of records, and "need to know" versus "right to know" issues for service personnel. From a child development perspective, and certainly of particular interest to the special education service system, is the nature of HIV infection as a disease which causes damage (encephalopathy) to the central nervous system.

Typically, most children with HIV infection have, or will acquire, significant developmental disabilities as a result of intrusion of the HIV virus into the central nervous system (3). Current research links pediatric HIV infection to prenatal and acquired encephalopathy (brain damage) resulting in neuropathological abnormalities in cognitive, motor, linguistic, psychosocial and sensory/perceptual development. Currently, HIV has become the greatest infectious cause of pediatric mental retardation in the United States (7).

In March, 1992, the Centers for Disease Control (CDC) reported 3,598 cases of Acquired Immunodeficiency Syndrome (AIDS) nationwide for children under the age of 13 (4). This number however, does not accurately reflect the number of children with HIV infection, the virus that ultimately causes AIDS, and tends to minimize an accurate count of children requiring special services. It has been estimated, that for every child with AIDS, there are several times that many children in various stages of HIV-related involvement (6).

Today, a disproportionate number of children with HIV infection come from low-income minority families in our inner cities, and acquire the virus from maternal transmission (11). Children requiring developmental services may be living with their parent(s), extended family members, in residential placements, foster care, or adoptive homes. Typically, the natural families who care for HIV infected children have a variety of basic needs in addition to those related to HIV infection, which may include: housing, food, substance abuse treatment, financial support, and transportation accessibility (16). Stabilizing the home environment is often a prerequisite to providing developmental services for a child with HIV infection.

The epidemic of pediatric HIV infection poses additional unique challenges to the developmental service system. The diagnosis of HIV produces major stress for the child's family, with a range of psychological reactions including: denial, anger, blame and guilt,

as well as extreme distress and anxiety . The confidentiality of an HIV diagnosis for many families is a primary concern. Persons with HIV infection may lose their family support, job, home, daycare, and/or access to some treatment options if health status is inappropriately disclosed (14). It is important to consider that each family responds to HIV infection and subsequent intervention options differently.

HIV RELATED DEVELOPMENTAL DISABILITIES

The appearance of developmental delays may be the initial presentation of neurological abnormalities in a child with HIV infection (7). HIV infection may not, however, be the only cause for developmental delay. The pediatric HIV population is also at risk for developmental consequences from other causes, such as: genetic factors, poor prenatal care, prenatal complications, substance abuse, low birth weight, nutritional deficits and environmental trauma. However, a rather unique feature of HIV-related disability is a progressive deterioration of the central nervous system contributing to unpredictable and fluctuating developmental abnormalities, in addition to a weakened immune system causing compromised health.

A child with HIV infection may be developmentally delayed at birth, or may remain developmentally age appropriate for a period of years (3). A warning sign of a change in developmental status can be an episode of particular compromised health with high fever, which should be followed by a developmental screening to detect any residual developmental complications. Compromised health alone however does not usually result in developmental delay, but it is the neurotoxic influence of HIV that causes brain damage which results in a loss of previously attained developmental milestones.

Both gross and fine motor deficits occur frequently among children with HIV infection. Common progressive motor delays include: inappropriate muscle tone (hypertonicity/hypotonicity), reduced flexibility and muscle strength, spasticity and poor control, and loss of previously attained motor milestones.

Cognitive impairments have also been found to be common in children with HIV infection. Cognitive abnormalities can be manifested as: decreased intellectual levels, specific learning disabilities, mental retardation, visual-spacial deficits, and decreased alertness.

Language delays are also found frequently in children with HIV infection. Oral structural and neuromuscular impairments, as well as cognitive deficits and environmental influences, may contribute to disability in the following communication domains: expressive

language (vocalizations/articulation), and receptive language (comprehension).

If a gained milestone is lost in any of the previously mentioned developmental domains, some spontaneous "rebounding" may occur, however, a return to the previous level of functioning is unlikely (15). This is much the same scenario as with stroke victims, where there is a episode of sharp decline, slow recovery for a few months, and then a plateau for a period of time below the original functioning level.

Currently, no psychopathological disorders have been described directly linked to pediatric HIV infection. However, psychological evaluation experience at the Mailman Center for Child Development has found it is common for children with HIV infection to develop emotional/behavioral concerns. Attentional difficulties can range from hyperactivity to autistic-like withdrawn behaviors and lethargy. It is typical for parents to have difficulty setting behavioral limits and/or they may overprotect their child, which can hinder the child's development of self-discipline while encouraging demanding or oppositional behaviors. Parents may be unaware of these pitfalls, as well as, how limit setting and behavior management can positively effect their child's quality of life.

PURPOSE OF DEVELOPMENTAL ASSESSMENT

The purpose of developmental assessment with this population is fourfold.

1) To identify and describe a child's strengths and weaknesses from a multi-disciplinary perspective

2) To determine the child's eligibility for intervention programming

3) To make specific recommendations for interventions strategies, delineating long and short term goals

4) To monitor a child's developmental status and response to intervention so programmatic adjustments can be made

Early assessment and early intervention is strongly recommended and may serve to minimize or delay the onset of HIV-related developmental delays. Children with HIV infection who are not yet presenting with compromised health or a developmental delay <u>are</u> at risk for developmental disabilities, and may become eligible for services under certain High-Risk eligibility provisions, such as PL 99-457 Part H.

CHALLENGES ASSESSING THE PEDIATRIC HIV POPULATION

Assessing young children with HIV infection can be very challenging and often imprecise due to child, family, and instrument/evaluator factors. Deliberate attention needs to be given to minimize these potential sources of assessment error. To not do so can result in inaccurate eligibility decisions and inappropriate strategies for intervention.

CHILD BASED FACTORS

Young children with HIV infection may be highly variable from day to day in their ability to participate in structured assessments. Possible causes for this excessive variability can be fluctuating health problems or attention/behavioral limitations imposed by central nervous system abnormalities. Questions about the reliability of a child's assessment performance often can be answered with collaborative information from parents, case managers, social workers and other health care providers who have knowledge of the child in other settings. However, the examiner's experience with this population and professional judgement is of special importance in obtaining accurate assessment information.

Health Status. Young children are unable to verbalize their complaints when they are not feeling well. It is common for children with HIV infection to have limited stamina and strength, and to be physically ill at the time of the evaluation with cold symptoms, fever, rash, infections, ear aches, or abdominal pain. The decision to reschedule the appointment should be based on the chronicity of the symptoms. Those with chronic or enduring symptoms may need to be evaluated while symptomatic, even though compromised health may limit test interaction and result in an under representation of potential. Children whose symptoms are intermittent or temporary should be evaluated in between illnesses.

Hospitalizations. A child may be hospitalized for extended periods of time. Evaluations or re-evaluations can be completed in the hospital, if circumstances warrant doing so. However, the examiner should be cautious that the assessment instrument may not be standardized for use in such a setting and the results may be difficult to interpret reliably.

Emotional/Social/Behavioral Status. Detecting abnormalities in emotional/social/ behavioral functioning is an important aspect of developmental assessment. When these types of disturbances occur they can seriously interfere with accurate assessment of other areas of development. Psychopathology within this population can be linked with central nervous system complications of pediatric HIV infection. But, behavioral and social concerns also can be a product of the milieu of the pediatric HIV population and may have a variety of environmemtal or reactive causes.

Changing Status. As medical and neurological factors change, the child's developmental status can be in flux. The child's changing status makes frequent assessment necessary for accurate program planning.

FAMILY BASED FACTORS

Caregiver's Health. The child's family plays an important role in the assessment process of children with HIV infection. Family members are responsible for accompanying the child to appointments, but may need assistance in arranging transportation. Parents are often important informants for some aspects of assessment, such as describing adaptive behaviors, and can also provide collaboration for behaviors observed or absent during the assessment process. Children living with natural parents will most frequently have a mother who has HIV infection. Mother's compromised health can prevent her from bringing in the child or actively participating in the assessment process.

INSTRUMENT/EVALUATOR BASED FACTORS

Standardization. Instrument difficulties vary depending on the type of instrument (i.e., norm versus criterion-referenced), the age of the child being evaluated, the area of development being evaluated, and the type of scored results an instrument yields. Most early childhood developmental instruments lack adequate administration standards, and have questionable representation from handicapped and minority populations (20). The type of score an instrument yields may not readily satisfy program eligibility needs. Programs may require a standard deviation, standard score, or percentile. Tests of motor and communication skills tend to provide only developmental age scores. A developmental age score is very difficult to interpret in regard to severity of disability. For example, a measured six month delay has different meaning for a one year old than a two year old child, and it may not be comparable across different developmental areas such as cognitive versus motor versus speech.

Reliability and Validity. With younger children standardized instruments are frequently criticized for their lack of predictability and reliability (20). The problem can be either within the instrument itself, the examiner's utilization of the instrument, or examinee test participation factors. In other words, is the child's score reflecting a true developmental delay or, is it reflecting primarily test limitations or test situation variables?

ASSESSMENT STRATEGIES

The assessment of young children with HIV infection warrants special considerations, some of which can be addressed through the following adaptations:

Concision and Coordination. Typically, assessments need to be completed quickly, primarily due to the child's limited stamina. Multi-disciplinary assessments are needed, but more than two assessment sessions are ill-advised. Therefore, a comprehensive test battery needs brief assessment procedures. When multiple examiners are used, they need to collaborate and share information. A parent should not be asked to answer the same questions twice, such as, "How was your pregnancy and delivery; How is your child's current health; Does your child sleep through the night; Does your child cry often?", etc. Also, it is important to minimize duplications in assessing different developmental areas since assessments of young children in different disciplines frequently have significant overlaps.

Flexibility. Assessment strategies need to be flexible. For example, tests selected in accord with a child's chronological age may be too advanced for a child's developmental level, justifying the use of a younger age range test to measure strengths and weaknesses. A useful rule of thumb is, if an adequate basal score can not be obtained, drop down in age to the next available test. Care should be taken to justify, in writing, why an adaptation was made, and to be certain it is accounted for in the interpretation of results. Another adaptation can be utilizing informants, such as parents, during a test session to collaborate their child's test performance to increase assessment precision.

Match with Setting. Appropriate assessment procedures for one setting may not be possible or appropriate in all settings. Multi-disciplinary or inter-disciplinary assessment approaches may be favored with less symptomatic children who are easily accessible in a service setting with better than adequate resources. Multi- and inter-disciplinary approaches allow for more individualized assessments, but are time consuming and costly. An arena or trans-disciplinary approach may be more advantageous for more symptomatic children who are less accessible in a service setting with limited resources. The trans-disciplinary approach allows for shorter assessment times, but may be overwhelming for a child or disturb families with confidentiality issues. Therefore, child based factors, family based factors, and service setting resources will dictate the most advantageous procedures for assessment. The most important emphasis when choosing an approach is looking at the child's development from a holistic or multi-developmental perspective.

Frequency. Frequent comprehensive multi-disciplinary assessments are important, particularly to detect changes in developmental status resulting from progressive neurological deterioration. Assessments and written reports need to be completed in a timely manner, as do intervention program adjustments. Young children with disabilities, particularly those with HIV infection, have a clock running against them in their wait for interventions. Assessments and interventions need to be done today not tomorrow.

ASSESSMENT INSTRUMENTS

Developmental assessments of children with HIV infection need to be comprehensive. Important areas for assessment are: cognitive, adaptive behavior, communication, gross and fine motor, behavioral\social\emotional, and perceptual. Assessments need to be conducted by appropriately trained professionals who have sufficient experience with early childhood disabilities and multi-cultural issues. They must be familiar in the administration of a variety of standardized instruments and possess well-honed clinical judgement skills. In general, due to child-based, family-based and instrument-based factors, young children with HIV infection are probably the most difficult of all populations to accurately assess. Certainly a critical issue is a basic inadequacy in the state of the art of assessment tools to measure a wide variety of early childhood disabilities.

Several factors need to be considered when choosing from the small number of standardized instruments available for assessing children with HIV infection:

Child's age. An age appropriate test should always be chosen first. If the child is unable to complete enough items on that instrument to determine a meaningful score, then a test for younger children should be implemented to determine an age score.

Child's level of functioning. The child's current health and behavioral/emotional status should be taken into account when choosing a test. For example, a child with attention deficits or limited stamina may require a test with a short administration time.

Available instruments. The instruments a site has available to them obviously limits the flexibility of testing. It is recommended that sites have access to at least two developmental screening instruments to help determine the need for further evaluation and/or referral. Standardized tests, that have been norm referenced using handicapped and culturally diverse children as part of their sample, are strongly recommended.

Professional judgement. The importance of clinical judgement when assessing children with HIV infection cannot be understated. Because of the previously mentioned test factors and examiner/examinee variables that can produce measurement errors, scores on standardized tests should as much as possible be corroborated with other evidence, such as agreement by an informant that a child lacks a certain functional skill. Clinical judgement also needs to accompany the results of standardized testing. The examiner needs to be sufficiently experienced in assessing similar populations to trust their judgement when there is reason to suspect invalid test results. The examiner may note developmental difficulties in young children for which there are no standardized instruments to measure, such as emotional deficits in fearfulness

or withdrawl, motor deficits in range of motion or tone, and communication deficits in voice quality or respiratory pattern.

PROGRAMMING CONSIDERATIONS AND INTERVENTION STRATEGIES

Children with HIV infection, while they remain healthy and developmentally age appropriate can be mainstreamed with no special program modifications, or specialized treatment from service personnel. However, when a child does become symptomatic with HIV-related complications special programming will become necessary. In a school based setting, appropriate services for a child with HIV-related developmental delays can be provided through the traditional Special Education program options with only minor modifications.

HIV positive children, whenever possible, should be served in the least restrictive environment in an integrated setting that includes non-HIV infected children (6,9). There is no evidence of HIV transmission from an infected child to other children or adults through casual contact in settings such as home , school, daycare, playgrounds or other places where physical contact occurs (1,9). However, in service programs for all children, regardless of HIV status , CDC recommends universal precautions for blood and body fluids containing visible blood (5). Universal precautions do not apply to feces, nasal secretions, sputum, sweat, tears, urine or vomitus unless they contain visible blood . HIV children should only be served in a segregated or a homebased setting when such an option is in the best interest of the infected child, usually for health concerns or lack of available appropriate centerbased options (1,6).

A comprehensive school-based developmental program is often multi-disciplinary, and can involve a combination of services such as: regular and special education, physical therapy, speech therapy, occupational therapy, health and medication monitoring by a nurse, counseling, behavior management or social work. The need for special programming is determined by the collection of current referral information, child/family background information, pertinent medical information, and comprehensive diagnostic developmental and educational assessments.

The important modifications to the usual Special Education service procedures most school districts employ, that are particularly necessary for children with HIV infection, include:

1. Diligent confidentiality of records, particularly those containing HIV-related information.

2. Frequent diagnostic re-evaluations, approximately every 4 months for children up to age 4 and every 6 months for children thereafter, to detect anticipated changes in developmental status.

3. Streamlined procedures for programmatic adjustments to accommodate a child's variable developmental and health status. It is not uncommon for a child to need Special Education service transition from a part-day program to a full-day program to a homebased program and back to school again all within one year.

4. School based decisions addressing "right to know" and "need to know" HIV status disclosure to service personnel, particularly teachers. Basically, there is no "right to know" of HIV status for any school personnel, and the law is quite clear on this issue (10). The "need to know", however, can be defensible only with parental consent, and is appropriate for those service personnel in a position to provide more effective decision making and intervention if they are aware of the cause for a child's exceptionality, such as: program administrators, therapists, school psychologists, and school nurses. While a child is asymptomatic and mainstreamed, essentially no personnel has a "need to know", but as the child's symptoms increase so in proportion does the number of school personnel who can better serve him/her if they "know". Disclosure intentions must be specific towards purpose and individuals to be informed, in writing and signed by the parent, and of limited time duration to comply with current legal boundaries (8). School attorneys should be consulted in the establishment of disclosure procedures.

CONCLUDING RECOMMENDATIONS

This presentation has emphasized much that is "needed" to accomplish accurate developmental assessments and facilitate appropriate intervention programming. These fundamental "needs" include:

* Need to understand, respect, and work within the family's value system, culture, knowledge of child, and rights to choose (17).

* Need to take into account the family's stress and psychological reactions (denial, anger, blame, guilt, and anxiety), and encourage support systems (16).

* Need to utilize procedures and safeguards to protect the child's and family's confidentiality, and legal rights to appropriate services that are free from discrimmination (2,8,13)

* Need for coordinated, streamlined, reliable, and valid assessment procedures to accommodate for the individual characteristics of the child, their family and the available resources of the service setting.

* Need for assessment strategies to anticipate transitional phases and minimize a disruption of services.

* Need for professionals from different disciplines to work together, share information and coordinate service delivery.

* Need for ongoing inservice training and emotional support for professionals working with children and families with HIV infection.

* Need for community awareness and education of pediatric HIV infection issues, particularly those associated with integrating children with HIV infection in developmental service programs.

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